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ABSTRACT

The difficulties faced by culturally different parents of multiply handicapped young children are considered, and examples of families of Chinese origin are offered to illustrate the impact of cultural styles and beliefs. The structure of the Chinese family is analyzed, its reaction to professionals and handicapped people explained. Guidelines for providing services to culturally different families are offered and three major goals of home intervention noted: (1) helping the parents to recognize the importance of working with the child, (2) encouraging independent behavior and helping the child to achieve specific developmental goals, and (3) demonstrating the value and importance of adult/child interactions. The use of play as an intervention medium is stressed. (CL)

WHERE SERVICE BEGINS: WORKING WITH PARENTS TO PROVIDE EARLY INTERVENTION. CONSIDERATIONS FOR THE CULTURALLY DIFFERENT

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Those alike in mind may differ in form. Those alike in form may differ in mind. The sage prefers what is like-minded and ignores what is alike in form. Ordinary men stick close to what is alike in form and keep their distance from what is like-minded. "We cherish and cling to what resembles us", they say.

Chinese Fable

The wisdom of the fable can be applied with ease to understanding the impact of cultural differences on the family with a multihandicapped child. The difficulties that we as professionals encounter have more to do with human relationships and communication than with cultural differences per se. These difficulties may be related to a number of factors including the language spoken in the home, the number of professionals and agencies involved and the ways in which information and advice are offered.

The development of parent professional partnerships is an ideal; it is also a process. Realizing the ideal and understanding the process are more subtle and complex than is usually recognized. The parents of a multi-impaired child are likely to be involved with a number of professionals and agencies, especially in large urban centers. If there is a primary worker, he or she may be a social worker who is unacquainted with the needs of the child. The agencies involved may or may not be consulting one another, and there may be disagreements of diagnosis, prognosis and treatments advised. What may be good practice in stimulation activities for the blind child may be inappropriate for the blind child with a neurological dysfunction.

It is extremely difficult for the well-educated middle class English-speaking parent to reconcile contradictory advice. It is overwhelming, confusing, and deeply disturbing for the culturally different to cope with as well. In recognition of the difficulties inherent in multidisciplinary models of service, the National Collaborative Infant Project (Haynes, 1978) recommended adapting the traditional interdisciplinary approach to the transdisciplinary model. In this model, "all aspects of the medical and medically related interventions are closely wedded to the educational and psychosocial components of development" (Haynes, p. 523). This is the model which views the parent as the "primary" teacher and intervenor. Accordingly, adherence to this model reduces the number of professionals providing one to one intervention. One member of the transdisciplinary team serves as team coordinator and facilitator and works closely with the family (Haynes, 1978). The value of this approach is being increasingly recognized.

The goals of intervention procedures have also changed. Rather than focus on the achievement of developmental milestones and individual skill competencies, the emphasis is now to increase the parent's ability to elicit a range of responses from their infants (Kysela and Marfo, 1983). This change has come about with the recognition of the importance of parent/infant interactions as the major process by which infants learn social, cognitive and communicative skills (Bruner, 1975).

Those behaviors seen as meaningful to the parents are those which can be practiced within the normal routine of the household (McCollum, 1984). Parent/infant interactions and social routines provide the foundations for later language acquisition and cognitive development. Because of their importance in the development of attachment and emotional bonding, they have become the basis of early intervention programs. Parents are advised in ways of increasing the child's responsiveness, providing additional stimulation, increasing communicative behaviors, facilitating sensory-motor development etc.. Techniques and procedures which can be combined with family routines are encouraged and facilitated. Adapting these services to parents who either do not speak English and whose cultural traditions and infant care practices differ from our own are presenting a different kind of challenge.

In many North American cities, a large number of families are recent immigrants from Asia, Central and South America. Cultural diversity has become the norm of large urban centers where native peoples from reserves and reservations as well as immigrants have tended to settle. Many of these people come from small villages and towns where the customs and attitudes towards the handicapped are shaped by deeply felt religious beliefs. The trauma presented by the birth of a severely handicapped child is intensified by culture shock and age-old fears.

Little attention has been paid in the literature to the effect of cultural beliefs and family practices on the delivery of early intervention services. Wilson, Mulligan and Turner (1983) noted that until basic family needs are met, it is futile to focus of the educational needs of the child. They also noted the importance of understanding the family organization and becoming aware of which family members are most responsible for the care of the child. In some homes, it is the grandmother who interacts most with the child. In others, it may be the mother, the mother's sister, or even an older daughter. Frequently, the father is the spokesman for the family. He is the one who attends professional and diagnostic meetings, but he does not directly care for the child (Wilson, Mulligan and Turner, 1985).

Experience with families of Chinese origin has provided rich instruction on the impact of cultural styles and beliefs; it has also been a source of insight into the cultural styles of North American society and how they sometimes interfere with the provision of supportive family services.

The Structure of the Chinese Family

The traditional Chinese family is the center of cultural and social life. In first generation families, the father is the undisputed head of the household. The wife is part of the husband's family and tends to be isolated from the outside world. Often the household may include the husband's parents and an unmarried brother or sister. If the husband's

parents do not live in the same h[illegible]. they live nearby (Lyman, 1974).

The traditional Chinese ha[illegible] deep sense of the "proper order of things". Notions of propriety are based upon filial piety, respect for elders and principles of familism (Lyman, p.167). Propriety is the principle which has enabled the generations to live together with a minimum of overt conflict. The formality interpersonal relationships extends to relationships outside of the family. Respect is accorded to authority figures. It is considered "poor taste" to disagree openly with professionals who come with offers of help. A family may feel deap shame when they perceive outside people as not approving of their treatment of their handicapped child. If there is disagreement between husband and wife about the care of the child, it is never displayed in front of strangers. It is a serious"loss of face" when a family dispute becomes a public matter (Sung, p. 179).

Social workers, teachers, public health nurses are perceived as government officials even if they speak Chinese. Government officials are not truly"trusted", especially by those families who have recently come from China. The professional who is an infant care worker may be faced with the choice of being perceived as an "official" to whom unfailing courtesy and respect is accorded or as an "auntie " or "uncle" if they present themselves informally. However, an "auntie" while well-regarded, may not be viewed as having the same expertise as the more "official" professional.

The blind in Chinese folk legend and history were feared or pitied. The blind person was not permitted to marry or have a family. The belief that there is something wrong with the family who have a blind child persists. When blindness is combined with other disabilities, family fears for the child are compounded. The family worries how the child will be treated by family and friends; they fear the cause of the child's condition and they worry about the child's future. Some people want to hide the handicapped child and refuse to talk to strangers about the child. This is especially true of older Chinese people who are afraid that the government will remove the child from the home. It is not uncommon to find handicapped children who have never been taken outside of the home, even for a walk or a trip to the food markets.

If people have to go outside of the Chinese community for help, they may not seek help at all. And because many people do not understand what can be done to help the child, they may regard the multi-impaired child as an infant even in his or her adult years. Unless advice is provided by someone who is trusted, even well-informed advice may be ignored. Professionals may feel frustrated, when after repeated visits to the home, they discover that their suggestions have been ignored.

The traditional Chinese family expects to provide full care for those who cannot care for themselves. Their ability to care for the dependent individual is a slurce of pride. No one would think of placing the child in a hospita l or institution.

In order to be of service to child and family, there needs to be a willingness to work within the situation one finds. Family attitudes and conventions must be accepted and not openly challenged, if one wants to continue the association with the family. Confrontation and critical attitudes are easily perceived and produce frustration on all sides. "It is always a mistake to confront Asian people with their lack of action. Confrontation is perceived as a deep insult. When the Chinese parent is made to feel ashamed and inadequate, it becomes easier for them to reject the advice and politely spurn the advice-giver, than to feel that they are making a terrible mistake," a Chinese person advised

Provision of Services to Culturally Different Families

It is far easier to make recommendations than to implement them. Sensitivity to the family and their love of their handicapped children can generally be assumed. Establishing a working relationship with those family members who are in contact with the child is by far the most delicate part of the process. Trust takes time to achieve and is nurtured by consistency and continuity of the personnel involved. The worker who comes to the home should be seen as a creditable source of information (Wilson, Mulligan and Turner, 1983). The home worker must consider how the family perceives the needs of the child and be aware of the situation of individual families. Middle class Chinese families are far more similar in their attitudes and approaches towards education than are families from smaller villages.

Advice must be credible and relevant to family values. For example in one situation where two dialects of Chinese and some English were spoken in the home, a clinician advised the family only to speak English to the child. The family were aware of the necessity for the child to learn English, but since they speak most comfortably in Chinese and value the Chinese language, they felt threatened by this advice, which also meant that they would have to ask the grandmother not to speak to the child.

The worker who comes to the home can be most effective by demonstration of techniques in the stimulation and care of the child rather than by giving verbal advice. By taking advantage of the child's natural setting, the home worker can build educational activities out of the child's normal routine.

The goals of home intervention

Home intervention has three major goals:

1. Helping the parents to recognize the importance of working with the child.
2. Encouraging independent behavior and helping the child to achieve specific developmental goals.
3. Demonstrating the value and importance of adult/child interactions.

Play is not often appreciated by adults as learning. Parents play with their children without realizing the rich education they are providing. By modeling play techniques and learning the "baby" games of the culture, the home teacher is able to show the parents that they are already engaged in

teaching the child. The common objects found in the home can make appropriate toys. It is important to demonstrate to culturally different parents that it is within their means to provide for their children.

The setting of specific goals should be done together with the parents. The first goals should be specific and within the reach of the child. There needs to be a willingness to focus on the behavior that is meaningful to the parent. It can be explained, with the help of an interpreter if necessary, how an advanced goal can be broken down into smaller goals. The parents also need to understand how some aspects of their child's development may take many months or even years to achieve.

When the parents realize the availability of the home teacher, they will come to value the association. With the first steps of progress will come a shared sense of purpose. Teacher and parents together can set goals that both agree are important for the child. When conflicts arise from cultural differences, they need to be made explicit. When they are not, there is conflict or feelings of frustration on both sides (Wilson, Mulligan and Turner, 1985). For example, compliance with adults may be perceived by the teacher as a necessary goal. But in a home where the practice is not to discipline a handicapped child, the teacher may find herself in conflict with the values of the home. In the context of an extended family, the impact of a handicapped child is often greatly reduced. The child's care is often shared by other family members.

In summary, the following recommendations have proved helpful and productive of rewarding relationships with culturally different families:

1. Allow time for trust and mutual understanding to be established.
2. Provide specific information to the family and be sure that the purpose of your visits are understood.
3. Set simple achievable initial goals.
4. Learn the child's routines and make suggestions that utilize activities such as bathing and feeding as opportunities for language stimulation and socialization.
5. Work within the framework that exists. Do not request special equipment. Make use of objects familiar to the child.
6. Encourage family members to show how they play with the child. Point out the values of those activities and expand them.
7. Understand the family's goals for their child and build on them slowly.
8. When demonstrating a technique, encourage family members to use them. Take your turn as observer.
9. Ask to learn the children's songs and games, learn them and incorporate them in your activities with the child.
10. Be positive and supportive. Give parents time to understand the purpose of intervention procedures.

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